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Tapping into the Health Wisdom of Crowd: Trends in Healthcare Social Networks

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Tapping into the Health Wisdom of Crowd: Trends in Healthcare Social Networks

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ABSTRACT

Web 2.0 technologies have given rise to Health 2.0, i.e., health social networks (HSNs). Citizens everywhere are flocking towards such HSNs that have the potential to empower them towards wellbeing and healthy living. This paper analyzes 37 best-known commercial HSN sites and evaluates them based on an existing evaluation criterion. As a result of a deeper understanding of the sampled HSNs, we develop a three-dimension framework to help categorize HSNs. Such a framework can aid in the design process of HSNs. The paper points out a need towards establishing best practices for design, information privacy and e-literacy aspects of evolving HSNs of the future.

KEYWORDS

Health Social Networks, Health 2.0, Patient empowerment, Social Networks

INTRODUCTION AND BACKGROUND

Information and Communications (ICT) technologies are changing healthcare in many ways. A variety of technologies are used to inform physicians, patients, and their families. They are innovatively used to prevent risky health behaviors, to manage diseases, to provide remote treatments, to provide a supportive network and more traditionally to provide a convenient means of communication between the professional care provider and the patient such as using e-mail. Unlike the traditional limited-level of patient involvement, patients are currently empowered and are able to make informed decisions regarding their health via enabling ICTs. Users cannot only consume information; they can also create and share information as well. User generated health content is uniquely referred to as Health 2.0. This term is used when Web 2.0 technologies are used within healthcare (O'Reilly, 2006). Although there is yet to be one agreed upon definition of this term, the content within Health 2.0 is information and tools that can be utilized by individuals and groups. This includes health related blogs, wiki's, social networks, and special interest online groups (Health 2.0 Conference, 2012). This research study primarily focuses on online social networks used in healthcare, known as health social networks (HSNs). These HSNs are quickly becoming pervasive with many of them having mobile applications on smartphones. Online social networks are electronic communities that are based on peer-to-peer communication, where users can share information, support one another, and join interest group discussions (Eysenbach, Powell, Englesakis, Rizo, and Stern, 2004).

Over the years, social networks have been notably acknowledged as useful tools to be utilized for health prevention programs (Orizio, Schulz, Gasparotti, Caimi, and Gelatti, 2010). Half a decade ago, social networks shifted to an electronic setting driven by the Internet accompanied by a sharp increase in users every year. Social network websites are user centric and are highly dependent on the user to create a profile, join interest groups and share information. Among such popular social networks are: LinkedIn with nearly 135 million subscribers in 2011, and Twitter with more than 100 million active users in 2011 (Parr, 2011). With regards to HSNs, dominant and popular social networks include: PatientsLikeMe for patients with about 100,000 members and Sermo for physicians which had over 10,000 registered physicians within just six months of going live (Sermo Inc., 2007).

Despite the growing interest towards social network sites, not much research has been conducted on their impact on users, overall optimal design, and extracting and analyzing data from such networks (Garton, Haythornthwaite, and Wellman, 1997). Garton et al. (1997) provides a good description on how to collect, analyze and utilize social network data. Moreover there are studies that highlight the effects of social networks on the user's health and the results vary among these studies. Some have reported positive health outcomes, while others reported no effects or highlighted the difficulty to observe such effects in online social networks. Powell, Darvell, and Gray (2003) discuss the various opportunities and benefits that virtual communities provide to their users. Users may be willing to participate and discuss their medical conditions more within

online social networks as they allow for anonymous communication. In addition, users access HSNs from all around the world which is valuable to patients with rare conditions, as such HSNs can bring together people that share the same rare symptoms allowing them to support each other and share experiences, thereby eliminating the physical distance barrier. Patients that share personal health data within online HSNs are more likely to better manage their disease, as they are personally involved in collecting and analyzing their personal health data. This reflects on their behavior as a result of such empowerment. The process of sharing, reviewing and providing some sort of assessment of the content improves the user's knowledge and utilization of such data. Patients are also able to provide valuable advice to their peers. Most importantly HSNs provide users with awareness and education that can lead towards positive behavioral change (Frost, and Massagli, 2008). In contrast, Eysenbach et al. (2004) reports no significant effects of computer based peer-to-peer communities on health, including both positive and negative effects. However, Eysenbach et al. (2004) does acknowledge the fact that such absence of effects does not conclude that HSNs have no effects. They suggest that this may be due to other reasons such as the difficulty of studying natural settings in a more controlled environment (Eysenbach et al., 2004). Another important note is that this study was conducted in 2004, before Facebook -the most dominant social network- was open to the public. Although there is no clear significant positive or negative effects reported in the literature, it is clear that online HSNs are changing medicine by empowering information seekers, both patients and caregivers, by providing them with highly connective tools and stripping down the boundaries of knowledge exchange (Giustini, 2006).

RESEARCH OBJECTIVE

The objective of this study was to provide a review of the various existing online HSNs. The research process included identifying the leading online healthcare social networks and examining each website's features. In addition, a literature review was conducted focusing on the role of social media in healthcare, Health 2.0 trends and the impact of online health communities towards users. We identify three dimensions to categorize HSNs. To our knowledge, there isn't any existing categorization of HSNs that the community can utilize to inform the design of HSNs and identify the needs of HSN consumers. Further; we adopted an existing evaluation framework to study such Health 2.0 sites and accordingly applied it to five representative HSNs. The paper concludes with a brief discussion pertaining to various considerations related to HSNs and suggestions regarding the future of such networks.

STUDY METHODOLOGY

In line with the study objective, a qualitative research approach was utilized. A literature review was conducted via online scholarly search engines (such as Google scholar, PubMed NCBI, JMIR and databases including ACM, IEEE, Web of Science, Emerald, ABI/Inform, EBSCOhost) to identify peer-reviewed articles concerning the use of online social networks for health related purposes. A review of the search results was conducted to identify relevant literature. In addition, a process of extracting information about the top HSNs from leading online news articles was conducted. The initial list of HSNs were identified by using Google search engine with the following keywords: health social networks, social networks for physicians, social networks for patients, health related social networks, social networks for clinicians, social networks for disease management, health information social networks. Additionally, a search for the top most used social networks for healthcare purposes was conducted by using keywords such as: top ten social networks, top health social networks, top social networks used by physicians, and top social networks used by patients. An extensive list of the top HSNs was extracted from the search results. Each HSN website was visited to analyze its features and services using a qualitative content analysis method. Out of the initial list of 66 HSNs, 37 HSNs were selected for further analysis (see Table 3 in appendix). The remaining websites were excluded for reasons such as the use of foreign language, websites not being active, or websites that are not healthcare-centric (e.g. Facebook). Some sites were accessible without creating accounts, for other we had to create accounts to gain access. The analysis included an evaluation of specific functional and non-functional requirements.

FINDINGS: ONLINE HEALTH SOCIAL NETWORKS

The findings of this study are based on a subset of 37 online HSNs. Each website was analyzed based on the features and services provided to the user. All websites were accessed during the month of November 2011 – February 2012 and were active and fully accessible during that time.

Requirements evaluation: Functional aspects

Almost all of the examined websites featured personal profiles, discussion boards and forums. All registered members have a personal profile that commonly includes a user name, a photo and some description of the member's medical condition. Only registered members can post content on the websites. Another observation was that social networks that target fitness and physical activity as well as diabetes tend to include a progress-tracking tool, which is commonly absent in other more general-purpose health social networks. Table 3 found in the appendix lists the 37 examined HSNs along with the identified common features for each.

Health Social Network Dimensions

Based on the analyzed sample, we identified three dimensions to help categorize online HSNs. The developed categorization was based on the observed criteria of the selected sample of websites as well as the criteria listed as important features of Health 2.0 technologies in the literature. This could help with identifying what are the best types of features and tools to include in a HSN according to the targeted user and overall intended use. Figure 1 illustrates the three dimensions each with its various components in relation to such networks. The first dimension that should derive the others is the "Targeted User".

There are various targeted users that HSNs focus on. HSNs that focus primarily on patients, such as PatientsLikeMe, is different from physicians-oriented sites such as Sermo. Others focus on families and friends of patients to enable them to get involved in the support process (e.g., WebMD). For each one of these components there are sub-categories. Some networks target patients with specific conditions or diseases, whereas other networks target patients with any kind of disease. Similarly the case with caregivers, there are social networks geared towards targeting one type of a healthcare professional, such as, physicians, nurses, medical students, or other ancillary health service providers.

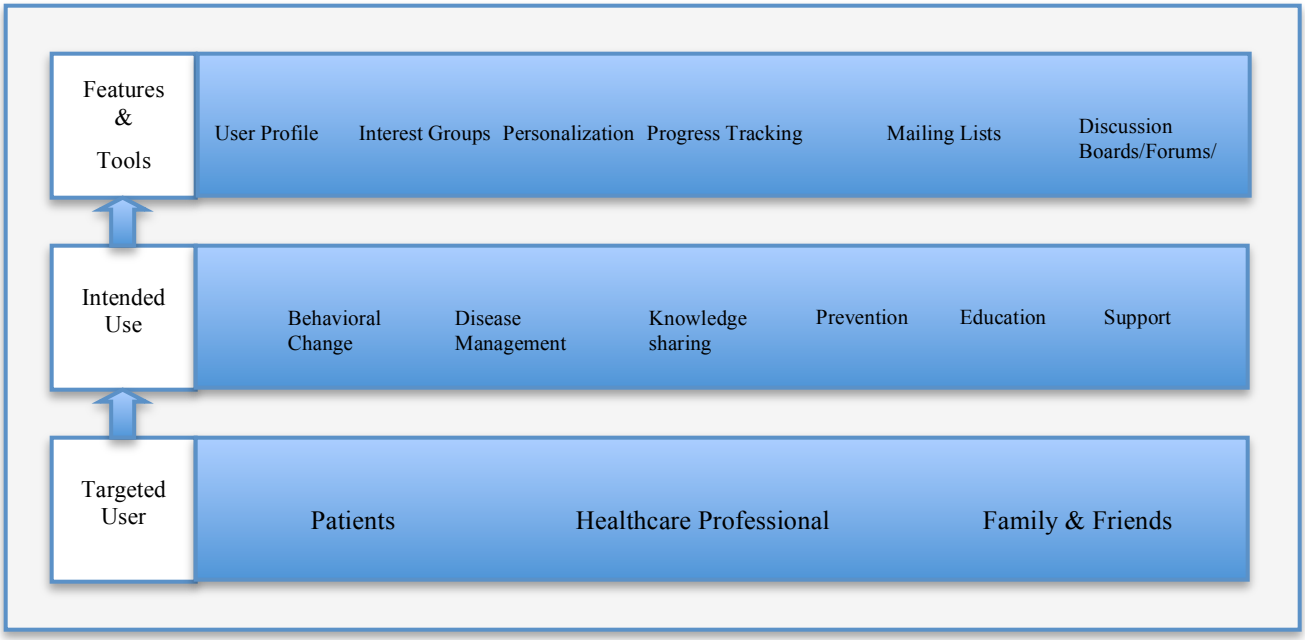

Figure 1 HSN Dimensions

The second dimension is the "Intended Use" of the social network. The majority of social networks aim to provide support to their users by connecting them with other users that share the same interest. Other HSNs targeting specific conditions aim to change the behavior of the user, such as smoking cessation communities, or communities that aim to prevent certain conditions such as minimizing disease related complications, such as HSNs targeting diabetics. Such communities enable the user to better manage their disease by providing them with supporting tools, such as progress tracking.

The third and final dimension includes the feature and tools embedded in such networks. Such features could be determined based on the targeted user, condition, and the goal behind using such a network. For example, HSNs targeting diabetics will commonly include a progress-tracking tool that enables users to monitor their glucose levels over time. A similar tool would also be present in social networks supporting fitness and physical activity where users can track their daily activity, steps and weight loss/gain. To better illustrate the various dimensions, Table 2 (see appendix) includes 13 social networks chosen from the initial sample of 66 and their distribution according to the three dimensions.

To our knowledge, there isn't any existing categorization of HSNs that the community can utilize to inform the design of HSNs and identify the needs of HSN consumers. The categorization schema presented here can aid in the design process of HSNs by identifying the most important features and functionalities of a successful HSN. Based on the targeted user, and therefore, intended use, on can identify the most relevant features and functionalities that any HSN designer should include.

Evaluation Criteria & Framework

In order to gain a better understanding of HSNs, it is important to evaluate the non-functional requirements and aspects of these web sites. We selected a sample of five HSNs for this evaluation component of the study. The five were selected based on each category pertaining to the "Targeted User" and "Intended Use" dimension. They are: (1) PatientsLikeMe, where patients are the targeted user group; (2) QuanitaMD, where clinicians are the targeted user group; (3) WebMD community, geared for patients, their family/friends, and clinicians; (4) Depression Connect, which focuses on educating and supporting the user; and (5) Stop Smoking Center, which focuses on behavioral change and prevention.

The existing evaluation framework we used has four criteria: information accuracy and quality, information presentation, information literacy, and information privacy & confidentiality. These four criteria were identified by Randeree (2009) as common challenges in most Health 2.0 technologies, and were therefore selected as a basis for evaluation. The first criterion, information accuracy and quality, was evaluated based on the network's content source and liability. This reflects the level of irrelevant information as well as any outdated information presented on the web site. The second criterion, information presentation, was evaluated by examining the appearance of information on the various websites. Various website design principles discussed by Aladwani and P. Palvia (2002), and Keeker (1997) were considered in the evaluation process such as content form and content personalization. The third criterion, information literacy, was evaluated by analyzing the content of the website in terms of its level of readability by the average targeted user. This was conducted by using an online readability literacy tool that checks for both, the grade level and the reading ease score. The readability index calculator using the Flesch-Kincaid[1] method was used (Flesch, 1948). Random text paragraphs were selected and inserted into the readability tool. The tool returns the readability scores for each given paragraph, the higher the score; the easier it is to be read. The fourth and final criterion, information privacy and confidentiality were evaluated based on the privacy policy public statement listed on the social networks. Table 1 provides a detailed analysis and corresponding outcomes related to evaluating these four non-functional requirements categories and criteria.

As expected in Health 2.0 technologies, users generate the majority of content and they are held liable for any information shared on such HSNs. Many HSNs are now moving towards greater personalization of the content. With regards to privacy policies, it is noticed that they vary from one HSN to another. It is highly recommended that users carefully read the privacy policy on the HSN they intend to use to share their personal information, as many users do not do so. Based on the readability test analysis, the information literacy presented on the selected HSNs was at the level required for the targeted intended user of the network. The analysis also indicated that the HSNs targeting patients had easier content to read in comparison to HSNs targeting clinicians. In light of the above, when designing new HSNs, one must consider the various discussed criteria and ensure proper inclusion in order to develop a high quality network.

THE ROLE OF DOMINANT SOCIAL NETWORKS IN HEALTHCARE

Although the focus of this research study is on social networks that particularly target the healthcare domain, it is imperative to note that there are other general social network sites that are dominating the headlines, such as Facebook and Twitter. Although these two popular social networking sites are not health-specific, embedded within them are a number of valuable health subs-sites, groups, and pages that are focused on patient empowerment and collaboration. Facebook and Twitter attract a large number of users and these two platforms are becoming the "go to" social networks for various needs, one of which is healthcare. Below we discuss these two networks.

Facebook

Facebook is currently the dominant social network with 845 million active users by February 2012 and is becoming a daily destination for a vast number of Internet users (Facebook, 2012). Facebook focuses on establishing connections amongst friends and people sharing the same interests. It is based on an extremely functional people network and is comprised of a number of functionality, features and applications. This, in turn, enables its diverse group of users to use it in different ways depending on their specific goals and intentions. Within Facebook, there are sub-sites and interest groups targeting specific domains in healthcare. For example Diabetes Awareness and You (DAY) subgroup carried a posting today – "We will start a campaign among school students on "Abuse of Medicine, Healthy Food, Child obesity & Diabetes" from February, 2012. We solicit YOUR support & co-operation". The Breast cancer site within Facebook reported, "Breast cancer has a 98% survivability rate when found early".

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[1] Flesch-Kincaid Grade level indicates the school grade that is expected to have been reached by an individual in order to understand and comprehend the text/content. (e.g. Grade level 7 means that you have to be at least a 7th grader in order to understand the content). Flesh-Kincaid Reading Ease score indicates how easy the text/content is to read. In general, easy text usually scores high (e.g. comic books), while more complex text scores low (e.g. legal documents).

	Information Accuracy/ Quality	Information Presentation	Information Literacy	Information Privacy & Confidentiality
PatientsLikeMe	Content source: • Users "patients" • Online resources Content liability: • The website is not responsible for content by users	• Content form: Text • Personalization: Ability to change profile view • Group discussion labeling: well organized and clearly labeled Page Design: Consistent colors and layout	Flesch-Kincaid Grade level: 15 Flesch-Kincaid Reading Ease score: 38	Privacy disclaimer: • Have the right to share patient data with partners Security settings/measures: • Users decide to whether to share identifiable personal information or not • Restricted data are not shared • Two privacy levels to choose from: **Visible:** Only the registered network users can see the profile and contact the user. **Public:** Both non-members and members can see the user's profile. However, only the registered network member can contact the user
QuanitaMD	Content source: • Users "Clinicians", institution faculty, and medical advisors • Online resources Content liability: • Advices users to confirm information reliable sources • Users are fully responsible for content & are held liable for any identifiable personal information posted	• Content form: Majority in multimedia form (Video + Audio), users able to comment in the form of text • Personalization: No • Group discussion labeling: well organized and clearly labeled Page Design: Consistent colors and layout	Flesch-Kincaid Grade level: 17 Flesch-Kincaid Reading Ease score: 18	Privacy disclaimer: • Does not share identifiable personal information to 3rd parties (with minor exceptions). • Only uses personal information for customization purposes • Shares aggregate data Security settings/measures: • Limited access by authorized users • Not liable to security issues related to 3rd party links
WebMD	Content source: Registered users "patients", medical writers and editors, physicians and health educators Content liability: The Independent Medical Review Board continuously reviews the site for accuracy	• Content form: Text • Personalization: Ability to change profile view • Group discussion labeling: well organized and clearly labeled • Page Design: Consistent colors and layout	Flesch-Kincaid Grade level: 14 Flesch-Kincaid Reading Ease score: 31	Privacy disclaimer: • Personal information will be kept private and not shared with anyone without your permission • Obtain consent before physically locating a use • Non identifiable data can be collected and disclosed to third parties in aggregate data format Security settings/measures: • User able to remove identifiable personal information from databases

	and timeliness			• Audit trails & internal monitoring of authorized employees
Depression Connect	Content source: Registered users and online news articles. Content Liability: Site not responsible for user generated content	• Content form: Text & Video • Personalization: Tailored user site experience • Group discussion labeling: well organized and clearly labeled • Page Design: Consistent colors and layout	Flesch-Kincaid Grade level: 13 Flesch-Kincaid Reading Ease score: 30	Privacy disclaimer: • Do not disclose identifiable personal information to third parties • Only snapshot of content is displayed on search engine lists • Collects aggregate data Security settings/measures: • Member has full control of profile privacy setting • Profile accessed only by community members
Stop Smoking Center	Content Source: Members, clinical advisors Content Liability: Do not guarantee accuracy or completeness of information	• Content Form: Text • Personalization: Customization based on quitter types / Personalizes your answers & creates user specified programs • Group discussion labeling: Not applicable • Page Design: Could benefit form some improvements with the graphical user interface (GUI)	Flesch-Kincaid Grade level: 11 Flesch-Kincaid Reading Ease score: 42	Privacy disclaimer: • Do not share identifiable personal information to third parties Security settings/measures: • Site does not specify any security measures

Table 1: Evaluation of five popular HSNs

Within the healthcare domain, Facebook has been used to share personal health information, to request medical advice and guidance, and most importantly to seek social support amongst common interest communities within the network. In a study aiming to evaluate the content of diabetic Facebook communities, it was found that common uses included questions and answers related to varying diseases, sharing personal experiences of patients, and providing feedback and advice related to the targeted diseases. Interestingly, as a result of the lack of accountability and the inability to authenticate users, the collection of personal data and related products promotions are common as well. This poses privacy concerns in addition to other related issues such as the accuracy of the presented information (Greene et al., 2010). However, despite the rising concerns of sharing personal health information in social networks, using such sites is greatly beneficial to the public's health when it comes to disease awareness and disease management. Patients are already realizing the value of using HSNs as the Pew Internet and American Life Project reported that about 20% of patients are going online to seek health information by visiting social networks to connect with patients that share the same disease(s) or interest(s), as well as to connect with medical experts (Shapiro, 2009). It is important to note that even though Facebook has a high number of users, the percentage of users seeking health information from these types of general social networks remains low. According to a survey conducted by Pew Internet and American Life Project in 2010, only 15% of online social network users have visited such sites to get health information. In response, one must include mechanisms to attract more users to the HSN space. This includes, easy to use tools for sharing and seeking health information, keeping track of personal health records, and supporting and motivating others with similar conditions (Eysenbach, 2008). This problem domain provides a great potential for research to be conducted. Research should focus on how current dominating social networks can be better utilized specifically for healthcare uses, and correspondingly, understanding how to increase the total number of users seeking health information within such networks.

Twitter

Twitter is a social network that is labeled as 'micro-blogging' for its short messages that are visible to one's followers and the public. It is currently drawing great attention with over 300 million users as of 2011 (Taylor, 2011). Unlike Facebook, Twitter is a social network that is structured in a more simple way, with less features and functionality in comparison to Facebook. It is a fast-growing site that is seen as a mass communication tool. As Twitter has grown, many healthcare organizations, clinicians and patients have been acknowledging its power and the mass communication mechanism it provides. Terry (2009) discusses the variety of ways Twitter can be uses by a physician. This includes communicating with colleagues, collecting medical information and sharing experiences amongst physicians, and obtaining conferences updates. In addition, many hospitals and healthcare organizations are reaching out to consumers through social media as part of their marketing strategy. This is in response to the increased number of patients that are influenced by social media in relation to their healthcare decisions. With this shift, healthcare organizations are now being pushed to adopt new technologies to keep up with the current trends and accordingly adapting new ways to reach out to their consumer base.

Many healthcare organizations are using Twitter to communicate news information and updates, as well as to attract followers to the organization's website. Mayo Clinic in specific is using Twitter to educate their followers on current research and treatments. Other organizations such as the CDC, utilize Twitter messages –also known as tweets- to spread awareness and prevention measures to the public in a timely manner. Another existing Twitter use includes getting information regarding clinical trials such as the case with TrialX (Terry, 2009).

There is great research potential in the Twitter world in relation to health leaders and health followers. Further investigating the characteristics of both entities and understanding the influence of the leader to their followers would be of great value in improving the spread of healthy behaviors in online social networks. This could be accomplished by utilizing the various analyses and mining tools of social media to further understand relationships between healthcare leaders and followers on Twitter. One example is Sprout Social, which is a web application that analyses and produces valuable reports on social media content in addition to the growing number of other functionalities that are easy to use. One study examined the characteristics of beginner Twitter users and how that would reflect their use of social networks for healthcare purposes. The results found that the increase of functionality and user unfamiliarity of the social network will reduce the chances of the user continuation and motivation of use. Beginner Twitter users need to understand the dynamics of the network prior to use and understand the value that is provided by increasing the number of "followings" and "followers" that are strongly related to the intended goal, in this case, healthcare. The follower seeking relevant health information need to find a mutual interest with the leader they follow, and must see value in the health related tweets that are expected to meet the user's needs (Oda, 2011).

CONSIDERATIONS AND ISSUES

There are a number of issues and considerations related to the use of online HSNs. One obvious issue is related to the privacy and confidentiality of shared health data. Most of the HSNs examined have explicit privacy policies listed on their websites. With regards to this, it is important to note that some of the HSNs clearly indicate that they have an open data sharing policy, such as PatientsLikeMe. Accordingly, in order for such networks to be successful and useful, users must be willing to participate and share their personal health information and experiences. Privacy concerns could reduce the willingness to participate for many potential users. On a positive note, most of these social networks do not require real names, and users can be anonymous. Therefore, in designing new HSNs, one must ensure anonymity of users in order to create a successful HSN environment. Another important issue is related to the level of professional monitoring of posted content. Users may post inaccurate and/or misleading information that could result in serious harm. Successful HSNs should provide continuous monitoring of content by professionals to keep users safe and increase the credibility of the network. One final consideration is related to the level of accessibility. The gap in access among people -digital divide- can hinder certain people from using such technologies. Powell et al. (2003) claims that people with low access to technology are expected to be part of the group with low health services. The authors also claim that the Internet opens the possibility for higher health access, such as telemedicine (Powell et al., 2003).

A very interesting opportunity that HSNs provide is related to the potential mass scale clinical trials. Pharmaceutical companies and drug manufacturers spend billions in testing new products and drugs through clinical trials. These trials enroll thousands of patients. Respectively, within HSNs, there are millions of consumers who are reporting drug side effects and other concerns to them. Therefore, such sites could potentially provide very valuable feedback to drug manufacturers. Such an activity can be thought of as a mass scale clinical trial.

FUTURE DIRECTION

HSNs are emerging technologies and a nascent research area. The impact of social networks on healthcare is not quite clear yet. Although many of the currently available studies are not showing any significant effects, the high adoption rate and increasing number of members using HSNs reflects the need for such concept. In one of the ihealth reports presented to the California Healthcare Foundation, Sarasohn-Kahn (2008) finds that the main driver for HSNs is the increasing demand for transparency and that social networks will take a vital role in supporting patients' decisions. This is a result of the increased empowerment and responsibility carried out by consumers. The future of HSNs headed towards more ties between healthcare entities and social media, an increased level of connectivity between digital communities, and greater development of physician to patient connections (Sarasohn-Kahn, 2008). However, HSNs must ensure regulation compliance such as HIPAA to avoid any legal issues.

This study scans the broad-spectrum of HSN landscape and highlights guidelines for designing successful HSNs. By understanding the user requirements amongst current dominating HSNs, a best-practice guideline will emerge. An important point to highlight is the need for more studies that focus on best practices, designs, and standards for developing HSNs. This is crucial in order to develop successful social networks that will meet and maybe exceed users' expectations and therefore improve their experience and outcomes. In light of the above, HSNs will greatly influence healthcare outcomes by empowering consumers, tapping the so-called "wisdom of crowd" to aid consumers to reach their health related goals.

REFERENCES

1. Aladwani, A. M., and Palvia, P. (2002) Developing and validating an instrument for measuring user-perceived web quality, *Information and Management*, 39, 6, 467–476.
2. Eysenbach, G. (2008) Medicine 2.0: social networking, collaboration, participation, apomediation, and openness, *Journal of Medical Internet Research*, 10, 3, e22.
3. Eysenbach, G. Powell, J., Englesakis, M., Rizo, C., and Stern, A. (2004) Health related virtual communities and electronic support groups: systematic review of the effects of online peer interactions, *BMJ*, 328, 1166-70.
4. Facebook. (2012) Facebook press. Retrived from http://www.facebook.com/press/info.php?statistics
5. Flesch, R. (1948) A new readability yardstick, *Journal of Applied Psychology*, 32, 221–233.
6. Frost, J.H. and Massagli, M.P. (2008) Social uses of personal health information within PatientsLikeMe, an online patient community: what can happen when patients have access to one another's data, *Journal of Medical Internet Research*, 10, 3, e15.
7. Garton, L., Haythornthwaite, C., and Wellman, B. (1997) Studying online social networks*, Journal of Computer-Mediated Communication,* 3, 1.
8. Giustini, D. (2006) How Web 2.0 is changing medicine, *BMJ*, 333, 1283–1284.
9. Greene, J., Choudhry, N., Kilabuk, E., and Shrank, W. (2010) Online social networking by patients with diabetes: A qualitative evaluation of communication with Facebook, *Journal of General Internal Medicine* 26, 3, 287-92.
10. Health 2.0 Conference. (n.d.) Defining Health 2.0. Retrieved from http://www.health2con.com/conferences/about-us/defining-health-2-0/.
11. Keeker, K. (1997) Improving Web-site usability and appeal: Guidelines compiled by MSN usability research. Retrieved from http://msdn.microsoft.com/en-us/library/cc889361(v=office.11).aspx
12. Oda, M. (2011) The characteristics of the use of twitter by beginners: Study of the applicability to the e-healthcare, Systems, Man, and Cybernetics (SMC), 2011 IEEE International Conference, 1268-1273. doi: 10.1109/ICSMC.2011.6083834
13. O'Reilly, T. (2006) Web 2.0 compact definition: Trying again, O'Reilly Radar.
14. Orizio, O., Schulz, P., Gasparotti, C., Caimi, L., and Gelatti, U. (2010) The world of e-patients: A content analysis of online social networks focusing on diseases, *Telemedicine and e-Health*, 18, 10, 1060-1066.
15. Parr. B. (2011) Twitter Has 100 Million Monthly Active Users; 50% Log In Every Day, *Mashable, Inc.* Retrieved from http://mashable.com/2011/10/17/twitter-costolo-stats/.
16. Powell, J., Darvell, M., and Gray, J. (2003) The doctor, the patient and the world-wide web: how the internet is changing healthcare, *Journal of the Royal Society of Medicine,* 96, 74.

17. Randeree, E. (2009) Exploring technology impacts of Healthcare 2.0 initiatives, *Telemedicine and e-Health*. 15, 3, 255–60.
18. Sarasohn-Kahn, J. (2008) The wisdom of patients: Health care meets online social media. California Healthcare Foundation. Retrieved from http://www.chcf.org/documents/chronicdisease/HealthCareSocialMedia.pdf.
19. Sermo, Inc. (2007) Online community created by physicians, for physicians: passes 10,000 registered users. Retrieved from http://www.sermo.com/news/pr/04/april/2/online-community-created-physicians-physicians-passes-10000-registered-users
20. Shapiro, J. (2009) Patients Turn To Online Community For Help Healing, National public Radio. Retrieved from http://www.npr.org/templates/story/story.php?storyId=120381580
21. Taylor, C. (2011) Social networking 'utopia' isn't coming, CNN. Retrieved from http://articles.cnn.com/2011-06-27/tech/limits.social.networking.taylor_1_twitter-users-facebook-friends-connections?_s=PM:TECH
22. Terry, M. (2009) Twittering healthcare: social media and medicine. *Telemedicine and e-Health,* 15, 6, 507–1

APPENDIX

Social network name	Primary targeted user	Intended use	Tools/features	Scope
Patients Like me	Patient Family	Online social support Education	Asses progress Access to clinical trials Interest groups	All conditions
ACOR	Patient Family	Online social support Education	Mailing lists	Cancer community
Disaboom	Patient Family	Educational Promotion	Information resources	Disabled people
Diabetic connect	Patient Family	Online social support Educational Behavioral change Prevention	Progress-tracking Diet recipes	Diabetic patients
iMedix	Patient Family	Online social support Educational Behavioral change	Interest groups Mailing lists Discussions	All conditions
inspire	Patient Family caregiver Organization	Online social support Education	Interest groups Discussions	All conditions
Daily burn	Patient	Social motivation Education Behavioral change Prevention	Fitness plans Nutritional tracking Social motivation	Fitness-oriented social network
Walk tracker	Patient Family caregiver	Prevention Social support	Group participation for communities and corporations as well as individuals Email List Tracking	All conditions
Sermo	Physicians	Social community Educational Collaboration Sharing medical information	Discussions Online events Online surveys	All Physicians
Rad rounds	Radiologists	Educational Sharing medical information	Interest groups Case based search, upload and ranking Multimedia Uploads	Radiology community
WebMD	Physicians Patients Families and friends	Educational Promotion Information sharing Prevention	Groups Discussions e-mail lists	Any person seeking health information
Ozmosis.org	Physicians	Educational Information sharing and Collaboration Finding new treatments	Discussion Information sharing Journal club Interest groups	All physicians
My family health	Patient and family	Educational Information Sharing	Creating family medical history trees	All conditions

Table 2 Examples of HSN dimensions

Feature HSN name	Personal Profile	Progress tracking/ Assessment	Interest Groups	e-mail lists /Inbox messages	Discussions/ Forums	Personalized Articles	Other
PatientsLikeMe	✓	✓			✓	✓	
ACOR				✓		✓	
Disaboom	✓				✓	✓	
Alliance Health	✓		✓	✓	✓	✓	Includes sub-networks
Imedix	✓		✓	✓	✓	✓	Medical dictionary
Inspire	✓		✓		✓		
Daily Burn	✓	✓			✓		
Sermo	✓	✓			✓	✓	Surveys/Panel events
RadRounds	✓		✓				Case based search
WEGO Health	✓		✓		✓		
WebMD Community	✓		✓	✓	✓	✓	
Ozmosis.com Community	✓		✓	✓	✓	✓	Tagging/Book-marking/ Knowledge feed
Daily Strength	✓	✓	✓	✓	✓	✓	
Healthy Place	✓		✓	✓	✓		
Twit2fit	✓		✓		✓		
Doximity	✓			✓	✓	✓	
Care Pages	✓		✓	✓	✓		
My Family Health	✓				✓		
Tu Diabetes	✓	✓	✓	✓	✓		
Weare.us	✓		✓	✓	✓		
Wellsphere	✓		✓		✓	✓	
Breastcancer.org	✓			✓	✓		
Diabetes Sisters	✓	✓		✓	✓		
DLife	✓		✓		✓		
Fat Secret	✓	✓	✓		✓		
Juvenation	✓		✓		✓		
MDJunction			✓		✓	✓	
My Open Care	✓		✓		✓		
Rare Share	✓		✓		✓		
Medhelp	✓	✓	✓		✓		
Psoriasis	✓		✓	✓	✓	✓	
Psoriasis Patients	✓		✓	✓	✓	✓	
Revolution Health	✓		✓		✓		
Quitnet	✓	✓		✓		✓	
Stop Smoking Center	✓	✓		✓	✓	✓	Personalized cessation
Cure together	✓	✓		✓	✓		
QuantiaMD	✓		✓		✓		

Table 3: List of the 37 HSNs Analyzed in this Study